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Issues and emerging trends related to the advancement of persons with disabilities

Report of the Secretary-General

Summary

The present report examines core issues and emerging trends in development approaches to the advancement of persons with disabilities in a broad human rights framework, and progress in furthering the goals of full participation and equality. A principal change noted is the shift in emphasis from biomedical and social welfare service approaches to persons with disabilities to the recognition of persons with disabilities as agents and beneficiaries of development of the societies in which they live. This was accompanied by the emergence of concern with environmental variables, viz. social, economic, institutional and policy factors, which can contribute to disability and thereby influence the participation of persons with disabilities in social and economic life, rather than the specific events, such as accidents, birth trauma, disease or genetic condition, or war that cause disability.

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I. Reformulations of the concept of disability

1. Prior to the adoption of the World Programme of Action, the general approach in policies and programmes was to associate disability with individuals. Action on disability was event-based, and activities mainly involved medical treatment, rehabilitation and social welfare services to enable the person with a disability to fit better into so-called normal societal structures. A related concern was prevention of specific causes of disability; little attention was directed to ways in which policies and institutions might create obstacles to full and effective participation of persons with disabilities as development agents and beneficiaries.[1] The goals of the World Programme of Action — full participation and equality — reflect recognition by the international community of the development approach to the advancement of persons with disabilities in a broad human rights context. The equalization of opportunities objective of the World Programme provides guidance for priority actions to translate the two Programme goals into specific outcomes. Development approaches to the advancement of persons with disabilities obtained added policy attention as a result of the statement by President Vicente Fox of Mexico at the general debate of the fifty-sixth session of the General Assembly. In his remarks President Fox called upon the international community to prioritize the fight against poverty and social exclusion. He observed that the world could not become more just if certain groups are excluded from this process, and stated that Mexico was proposing the establishment of a Special Committee to study the question of an international convention on promoting and protecting the rights and dignity of persons with disabilities.[2]

A. Development approaches to the advancement of persons with disabilities

2. Reformulated concepts of disability direct special attention to the importance of removing barriers and promoting accessible environments, so that people with a disability are better able to participate, on the basis of equality, in social life and development. Participants in a United Nations interregional expert meeting on sustainable livelihoods and persons with disabilities, hosted by the Government of the Republic of Indonesia at Jakarta (15-17 January 2002), identified three categories of environmental barriers to the promotion and realization of sustainable livelihoods by persons with disabilities: (a) adapting to a disabling condition and maximizing functional capacity, (b) interacting with the community and with society, and (c) gaining access to social and economic activities that give meaning and purpose to life. Addressing these barriers would involve support for rehabilitation strategies that maximize the functional (and social) capabilities of people with disabilities; formulation of inclusion and empowerment strategies to facilitate the full and effective participation of persons with disabilities in their communities, societies and economies; and promotion of architecture, engineering and design strategies that prevent or remove unnecessary barriers and handicapping conditions in the infrastructure, which includes the built environment, transportation systems, the workplace, and information technologies and communication systems.

3. Research studies suggest that there is no single formulation of the developmental approach to disability. Some studies tend to view persons with disabilities as a minority group, more because public attitudes make them the object

of prejudice and discrimination than because of the existence of physical barriers to their full and effective participation.[3] The minority-group model considers all facets of the environment to be influenced by public policy, since policies reflect societal attitudes. Existing features of the physical, social and economic environment that have a discriminatory impact on persons with disabilities cannot be viewed merely as happenstance or coincidence.[4] Action is required to address public attitudes that allow and reinforce prejudice and discrimination in society. Other studies argue that human rights approaches to disability are different from those that consider environmental factors.[5] The view is expressed that human rights approaches focus on the rights to which all people, whether disabled or non-disabled, are entitled. Human-rights approaches analyse how society marginalizes persons with disabilities, and how the social environment could be changed and become more inclusive.[6] The common theme in development approaches is the prevention of exclusion — or abandonment to institutional settings — and the promotion of inclusion, self-determination and full participation and equality.

B. Accessible environments

4. Accessibility was identified in General Assembly resolution 52/82, of 12 December 1997, as a priority in furthering the equalization of opportunities for persons with disabilities. The experience suggests that a focus on accessibility is an effective approach to reversing exclusion and to enhancing equalization of opportunities in a positive and sustainable way. The complexity of the issue requires that the concept of access must be addressed in a systematic way, if it is to add value to policy processes.

5. Access is not an act or a state but refers to freedom of choice in entering, approaching, communicating with or making use of a situation.[7] The environment is either the large whole of or parts of the situation that is being accessed. Equal participation would be available if equalization of opportunities to participate were provided through measures that enhance accessibility. The elements of accessibility are attributes of environmental availability but are not environmental characteristics. For instance, in the field of health care, Professors Pechansky and Thomas define access as "a concept representing the degree of 'fit' between the clients and the system."[8] Five characteristics of access to health care are identified: availability, accessibility, accommodation, affordability and acceptability.[9] Research in the field of rehabilitation of persons with a disability has identified five environmental characteristics:

(a) Accessibility — can you get to *where* you want to go?

(b) Accommodation — can you do *what* you want to do?

(c) Resource Availability — are your special *needs* met?

(d) Social Support — are you accepted by *those around you*?

(e) Equality — are you treated *equally* with others?[10]

6. Accessibility characteristics identified don't so much provide a basis for classifying or ranking environments as represent a scheme to classify the different ways in which people interact with environments. Accessibility is only one of the five characteristics of accessible environments identified.

7. Universal design also provides a basis for assessing accessibility with reference to interactions between people and the environment. Since the value proposition of universal design is the design of products and environments to be usable by all people, to the greatest extent possible,[11] universal dimensions of access should: (a) recognize the social context, (b) consider the situation of the whole person, (c) take age and cultural factors into account and (d) support analyses in terms of the individual and the environment. Building on the handicap classification developed by the World Health Organization,[12] an expert meeting organized by the United Nations in cooperation with York University (Toronto, 17-19 June 2002) considered several dimensions by which to assess access:

(a) Orientation (who) — do you have information you wish?

(b) Independence (what) — do you choose what you wish to do?

(c) Mobility (where) — do you go where you wish?

(d) Occupation of Time (when) — do you engage when you wish?

(e) Social Integration (with whom) — are you accepted by others?

(f) Economic Self-Sufficiency (with what) — do you have the resources you need?

(g) Transition (change) — are you prepared for change?[13]

8. One implication of environmental appraisals based on universal dimensions of interactions between people and their environments is that they allow review and assessment of accessibility variables and identification of options to reduce social exclusion and ensure the rights for all. Accessibility is not the concern of a specific social group but is an essential prerequisite for the advancement of all.

C. Reconsideration of vulnerability

9. There is a tendency for some outcome documents of international conferences and summits to include persons with a disability among the set of vulnerable population groups, as in the Plan of Implementation of the World Summit for Sustainable Development (Johannesburg, 26 August-4 September 2002).[14] This usage reflects the minority-group model of disability and the perception that limitation of physical, sensory, motor development abilities places people at risk. However, vulnerability is not a topic considered in the World Programme of Action. The data suggest that disability is a normal aspect of life; all kinds of disabilities can happen to all types of people at all stages in their normal lifecycles.[15] The task for analysis is to reconsider vulnerability as a policy variable that affects all.

10. The Commission for Social Development at its thirty-sixth session (New York, 10-20 February 1998) considered vulnerability in the context of strategies to promote social integration. The Commission noted that vulnerability affects all, since all are exposed to a variety of risks but that risks are not evenly distributed among the general population. The Commission also noted it was possible to identify three dimensions of vulnerability: (a) risk dimension, or the probability of information and communications technologiesimization; (b) state of mind dimension; and (c) impact dimensions. In its agreed conclusions the Commission noted that policies to address vulnerability, inter alia, need to be based on a proper

understanding of the risk of poverty and social exclusion; should aim to strengthen community-based networks and institutions of civil society; need to account for territorial aspects of vulnerability, as between rural and urban areas; and need to direct special attention to childhood education at all levels so that equal educational opportunities at levels for persons with disabilities can be ensured.[16] The Commission expressed the view that a major determinant of vulnerable population groups is the extent to which policies and programmes are inclusive, are supportive of communities and families and ensure equal opportunities to programmes and services for all. People with a disability are vulnerable if there is loss or limitation of opportunities to take part in the normal life of the community on an equal level owing to physical or social barriers.[17]

D. The new universe of disability

11. Both the World Programme of Action and the Standard Rules define persons with a disability with reference to terminology developed by the World Health Organization (WHO) in its International Classification of Impairments, Disabilities and Handicaps (ICIDH). WHO-ICIDH is based on the health experience; its aim is to describe the consequences of disease, injury or disorder at the level of specific body function (biomedical status), of the person (body structures and functions) or of society (impairment, disability and handicap).[18] WHO-ICIDH implies a causal link between impairment, disability and handicap unmediated by environmental factors, which do in fact influence the incidence of disability in society.[19]

12. In contrast to the health experience-based WHO-ICIDH some analysts have elaborated a life spheres approach to disability, which represents a shift in analytical focus from physical, sensory or development abilities to opportunities in society. As presented in the table below, the units of analysis are the person, family, society and the larger environment. The analysis introduces life cycle changes rather than the static analysis of WHO-ICIDH.

Evolution of handicap from ability focus to access to life situation

Handicap category	*Ability of individual definitions*	*Access to life situation*
Orientation	Receive and respond to surrounding signals	Exchange of information
Physical independence	Sustain existence without aids or assistance	Choice
Mobility	Move about effectively in surroundings	Travel
Occupation	Occupy time in a customary manner	Actual use of time
Social integration	Participate in customary social relationships	Actual relationships
Economic self-sufficiency	Sustain socio-economic activity	Economic resource control
Transition*		Preparation for life changes

Source for handicap categories and ability of individual definitions: World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification relating to the Consequences of Disease* (Geneva, World Health Organization, 1980).

**N.B.* "Transition" is not an original WHO-ICIDH handicap category.

13. The shift in analytical focus from individual abilities to life situation opportunities represents a shift in focus from a particular activity to the day-to-day results for an individual operating in his or her environment. The key issue is access by the individual to choice in decisions about their well-being and livelihoods without recourse to aid or assistance. In this sense, economic self-sufficiency is not viewed in terms of an individual's ability to earn income but in terms of the capacities of the individual to influence and control economic resources. Opportunity variables apply not solely to individuals. Disability policies and programmes on the families of persons with disabilities influence the range of choice that families have in terms of travel, use of time, social relationships and control of economic resources. Policies and programmes can be examined in terms of outcomes from the disability perspective and not with reference to specific population groups.

14. A second component of the new universe of disability relates to transition, particularly population ageing. This was discussed first in the third review and appraisal of the World Programme of Action (A/52/351) and analysed in the "Madrid International Plan of Action on Ageing", which noted that the proportion of the world's population of persons aged 60 and over is expected to double between 2000 to 2050 from 10 to 21 per cent; in developing countries the proportion of older persons is expected to increase from 8 to 19 per cent by 2050 (A/CONF.197/9, Resolution 1, annex II). Transition and preparation for life changes as a result of a

decline in some physical and sensory capacities is a recognized fact of ageing. However, this is not a sufficient basis for including older persons among the set of persons with disabilities. The policy issue is that as populations age, the percentage of the population that experiences some degree of impairment — but which is not disabled — will increase. An important planning issue is the formulation and budgeting of options to promote accessible environments and opportunities to acquire[20] assistive devices.

15. The third component of the new universe of disability relates to the need to address population groups that include persons with mental health issues and those with active, acute conditions.[21] For instance, the Special Rapporteur on Disability has directed special attention to the situation of persons with developmental and psychiatric disabilities in his second monitoring report (E/CN.5/2000/3 and Corr.1). He noted that they are often among the most marginalized in the societies in which they live; important tasks on behalf of this group include preparations for social integration, as well as improvements in living conditions for those who require institutional care.

16. Similar issues are encountered with regard to persons with active, acute conditions, for instance those who suffer HIV/AIDS. Fighting acute disease requires resources that might otherwise be available for implementing policies and programmes on disability. Many people who are surviving with AIDS and other acute diseases often need services required by people with traditional disabilities. In some countries, national disability policy or law protects persons with an active, acute condition. Countries that have yet to adopt policy guidance or legislation are presented with the urgent task of formulating appropriate policy options on protecting the rights and dignity of persons with acute, active conditions. However, including persons with active, acute conditions among the set of persons with disabilities highlights the link between disability and health status. Traditionally disability advocates have sought to decouple disability and health issues, urging that society reject the notion of people with disabilities as "sick". There is a growing body of evidence that suggests that persons with disabilities are at greater risk of acquiring what have been termed secondary conditions. Formulation of options for prevention of secondary conditions for persons with disabilities is an important goal of public policy and introduces the urgent need to reconsider the conceptual bases and terminology on disability.

17. One implication of the several dimensions of the new universe of disability is the need to reconsider — and update appropriately — the estimate that one person in ten in the population had a disability, contained in the World Programme of Action (A/37/351/Add.1 and Add.1/Corr.1, para. 37) and many other policy and programme documents to date.

II. Collection and analysis of data and statistics on persons with disabilities

18. As discussed in the preceding section the United Nations Statistics Division has made important contributions to implement recommendations of the World Programme of Action on monitoring and evaluation (A/37/351/Add.1 and Add.1/Corr.1, para. 198) as this relates to the development of disability statistics and the collection of data related to disability.[22] These activities have been guided at the

international level by the work of the World Health Organization on disability terminology, in particular the International Classification of Impairments, Disabilities and Handicaps (ICIDH)[23] and its recently adopted International Classification of Functioning, Disability and Health (ICF).[24] Results of the disability statistics work of the United Nations was published as the *Disability Statistics Compendium* of the United Nations (DISTAT),[25] with recent additions and improvements to the database being published on the Internet < http://unstats.un.org/unsd/disability/>.

19. However, 20 years after adoption of the World Programme of Action, it still is not possible to state with precision what percentage of the population is disabled. The reason is that there remains observed variation in the disability data collected by the United Nations, which is the result of different definitions, concepts and methods used in countries. Analysts cannot draw comparisons about the nature and extent of disability within or between countries or make social and economic comparisons between disabled and non-disabled populations. Following the WHO-ICIDH logic, the 1990 *Compendium* found countries collecting data on the basis of a disability-approach or an impairment-approach. Countries using impairment approaches would collect data on the blind, deaf or mute or both, and physical disabilities, while those collecting data on the basis of disability approaches would group data with reference to broad disability categories, such as mobility, agility, seeing, hearing, speaking, other (limited abilities due to learning, emotional, psychiatric or developmental delay).[26] Other countries included information on persons with mental disabilities as well as the sick — following the disease and event-based causal logic of WHO-ICIDH. Differences in the screening used to obtain disability data have contributed to significant biases in estimates of disability as a proportion of the total population, in gender studies, in comparisons of social and economic characteristics, and in economic activity.[27] Inadequacies in disability data, whether stemming from definitional problems or from collection and measurement problems, hamper efforts to place disability issues on mainstream policy agendas at all institutional levels. Disability issues receive limited support because disability experts and advocates are forced by inadequate or non-existent data to participate in policy debates in which they are unable to describe accurately the conditions differentiating disabled from non-disabled populations.[28] Accurate data are indispensable to the development of informed disability policies and strategies capable of increasing social and economic opportunities for people with disabilities.

20. International efforts are under way to address pressing problems in disability data collection, viz. lack of agreed disability definitions and lack of uniform disability data collection protocols. For instance, in connection with preparations for the year 2000 round of population and housing censuses, the United Nations prepared revised census recommendations[29] that for the first time recommended coverage of the topic of disability in national censuses and surveys. To measure the disability dimension the United Nations recommended that a person with disability should be defined as a person who is limited in the kind or amount of activities that he or she can undertake because of ongoing difficulties that are due to a long-term physical condition, mental condition or health problem; only disabilities lasting more than six months should be included.[30] Owing to the limited space available in a census, the United Nations further recommended that a disability-oriented question could be asked (as opposed to an impairment or handicap question).

21. Most discussions on further development of disability statistics focus on definitions derived from the impairment and disability variables of WHO-ICIDH. In contrast, the new universe of disability would suggest the need to consider measures of critical life areas for equalization of opportunities. These could include measures with regard to whether persons with disabilities are empowered to make decisions independently in their lives, have control over their use of time, have control over economic resources and are prepared for major changes. Results in these areas often determine whether outcome targets for equalization of opportunities will be achieved. Because each individual's situation is unique and influenced by many factors, such as age, culture or location, it is important to understand the particular factors affecting each disabled person in his or her environment. If the interactive nature of the concept is not assessed, then an understanding of the critical aspects of barriers to reducing disadvantage may be lost.

22. Definitions related to handicap are an emerging area of methodological concern, since they may be confused with the target areas for equal participation of the Standard Rules. Some analysts have argued that there are two basic approaches to the evaluation of handicap: (a) estimation of the gap between persons with and without disabilities, and (b) estimation of specific reductions in life roles.[31] As discussed in the preceding section, environmental variables can influence both of these dimensions — and enhance or block achievement of the goals of the World Programme of Action — so all dimensions need to be considered when measuring progress and obstacles in the advancement of persons with disabilities. Life sphere dimensions, measured properly — not as individual abilities but as the actual circumstances in which people find themselves and which may place them at a disadvantage — can provide critical measures for the design of policies and programmes that target specific life areas that will have the greatest impact on equalization of opportunities.

III. Advances in technologies

23. Progress reports of the Secretary-General on implementation of the World Programme of Action submitted to the fifty-fourth (A/54/388 and Add.1) and fifty-sixth (A/56/169 and Corr.1) sessions of the General Assembly drew special attention to the role of technological advances and the promotion of accessible environments for all. The reports noted the policy guidance provided by rule 5 of the Standard Rules on accessibility in both the physical environment and information and communication technologies. The reports also presented a value proposition for promotion of accessible environments, viz. best total solutions for action on environmental accessibility by, for and with persons with disabilities (A/54/388/Add.1, para. 2).

24. Environmental accessibility affects all. Its emergence as a major concern reflects the shift in emphasis from medical models of disability, and their emphasis on care, protection and assisting persons with disabilities to adapt to "normal" social structures, to social and development models, with their focus on empowerment, participation and modifications of environments to promote equalization of opportunities for all. Technological advances in the physical environment are reflected in the expanded range of materials that promote accessibility for all in terms of ease of use, durability and ergometric design. Equally important contributions were made by countries that published on the Internet guidelines for

the planning and design of accessible environments in order to promote public awareness and train national personnel; this included Lebanon (for Beirut) http://www.un.org/esa/socdev/enable/designm/, Malta http://www.knpd.org/sxsguidelines/xsgl.htm and Peru http://www.un.org/esa/socdev/enable/guiadd/.[32]

25. The rapid pace of development in information and communications technologies has significant social and economic implications for countries; it can also influence the participation of persons with disabilities in social life and development on the basis of equality. The role of information and communications technologies in the context of the development of a knowledge-based global economy in the twenty-first century was the topic of the high-level segment of the substantive session of 2000 of the Economic and Social Council, which adopted a ministerial declaration on the role of information technology and development.[33] The Declaration noted that bridging the digital divide, creating opportunities to access information, and developing knowledge-based economies is largely determined, inter alia, by education, national capacities to generate and use knowledge, information connectivity and content, and policy and legal/regulatory frameworks. The Declaration makes several references to the "digital divide" and the importance of access to such technology to achieve social and economic goals, but it makes no reference to the situation of persons with disabilities nor does it provide normative or substantive guidance on policy options to promote accessible information and communications technologies for all.

26. Recent national experiences suggest two points are important in the design of disability-sensitive policy options related to accessible information and communications technologies: first, access to such technologies is not the same as accessible information and communications technologies for all; second, the term "digital divide" refers to the continuum of digital connection capabilities in countries and not to a particular state prevailing among countries. Access to information and communications technologies mainly concerns hardware and telecommunications infrastructure, while accessibility refers to the design parameters and capacities of such technologies to accommodate the needs, preferences and special abilities of each user. Accessibility is concerned with the environmental setting for information and communications technologies, which includes the policy and legal frameworks, relative level of development, institutional arrangements and national capacities to plan and manage such technologies and to produce content, and the state of information and communications technologies infrastructure and associated technologies.

27. Accessibility is a priority concern identified by the first session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities (New York, 29 July to 9 August 2002), established pursuant to General Assembly resolution 56/168. In the resolution submitted by the Ad Hoc Committee for adoption by the fifty-seventh session of the General Assembly on its future work, the Committee directs special attention to the role of accessible information and communications technologies and "strongly recommends the Secretary-General to implement some measures ... to facilitate accessibility to United Nations premises, technology and documents". The Committee invited, "among others, persons with disabilities and experts, to present proposals."[34]

28. In his progress report to the fifty-sixth session of the General Assembly, the Secretary-General cited advances in medical research as an emerging issue to be considered in his fourth review and appraisal of the World Programme of Action. Advances in medical research, genetics and biotechnology, in particular, have important implications for disability, privacy, ethics and human rights. Progress in genetic research, beginning with the description of the structure of DNA (deoxyribonucleic acid) nearly 50 years ago and recent developments in the Human Genome Project[35] has resulted in improved understanding of the genetic bases of many diseases. This new genetic knowledge has many applications in health care, ranging from testing and early detection of susceptibility to diseases, evaluating drug responses, to possible cures to diseases (gene therapy). Some are of the view that the benefits of genetic knowledge, coupled with reduced costs for genetic screening and testing, have been exaggerated and present social and ethical challenges. Inclusion International, a non-governmental organization advocating on behalf of people with intellectual disabilities, has argued that genetic research can be beneficial but that it can also undermine human rights, especially for people with disabilities.[36] Advances in biotechnology, such as stem-cell therapy, reproductive cloning and chromosomal manipulation, are technologies of great potential, but they also raise complex ethical and biomedical issues, which can outpace current legislative and policy frameworks.[37] Some analysts have identified a set of principles that they believe ought to guide further work in the fields of genetic research and biomedicine: justice, non-discrimination, diversity, and autonomy with informed decisions. The principle of justice holds that every person has the right to develop according to his or her potential. The principle of non-discrimination holds that everyone has the right to respect for who he or she is and to live as an equal citizen. The principle of diversity promotes making the world available to all and not only to those defined by notions of perfection and normality. The principle of autonomy affirms that people have a right to be independent and to make their own decisions.[38]

IV. Next practices: building national capacities for the equalization of opportunities in the mainstream

29. Capacity-building for the equalization of opportunities obtains support from the United Nations system within a narrow range of sectoral concerns, mainly social welfare and services, functional rehabilitation and social protection. Capacity-building in the field of disability gained added attention as a result of findings presented in the first monitoring report of the Special Rapporteur on Disability (A/52/56, annex), who observed that he had found limited efforts during his first mandate (1994-1997) "to integrate disability measures into ... mainstream activities." He noted:

> "... There is a great risk that disability measures once again will be left out or marginalized in those development programmes launched in response to the [major] United Nations [conferences and summits] follow-up. ... It would, for instance, be extremely discouraging if programmes for poverty eradication were to be launched without measures to support persons with disabilities. To strengthen and integrate disability measures into the mainstream of technical cooperation, including UNDP [United Nations Development Programme], the World Bank and other financial institutions, is one of the most urgent measures

of all in the future implementation of the Standard Rules." (A/52/56, annex, para. 135).

30. Efforts to address capacity-building for equalization of opportunities have mainly proceeded with the support of special funds, such as United Nations Voluntary Fund on Disability, whose exiguous resources have been augmented on a project-specific basis by the intergovernmental Arab Gulf Programme for United Nations Development Organizations (AGFUND).[39] This was discussed in the report of the Secretary-General to the fifty-fourth session of the General Assembly on the implementation of the World Programme of Action (A/54/388/Add.1), in which he described support to catalytic and innovative action to implement the capacity-building guidance contained in General Assembly resolution 52/82 (para. 8) as a mainstream issue and implications for the equalization of opportunities in the priority areas of accessibility, social services and safety nets, and employment and sustainable livelihoods. The report noted that the capacity-building strategy was characterized by (a) its focus on constituency-driven initiatives, in cooperation with Governments, that address a particular disability issue in a catalytic and innovative way; (b) its cooperation with project agents to formulate and implement time-bound, operational proposals for action in line with priorities identified to further equalize opportunities; and (c) its documentation of lessons learned (and obstacles encountered) for study by other interested parties, and their publication on the global Internet to facilitate access by all. The report identified three lessons of Voluntary Fund support for disability-sensitive capacity-building in the mainstream: (a) the essential role of concise, strategic policy guidance by Governments on priorities and means of execution for national capacity-building, (b) the critical contribution of partnerships at all levels to facilitate consultation, coordination and execution, and (c) the need for rapid and appropriate responses in terms of technical and financial assistance, on a small-scale, to facilitate quick disbursement as venture grants.[40] The experience of the Voluntary Fund suggests that disability-sensitive policies provide an essential enabling framework for sustainable development for all. Mainstream investments in building national capacities and institutions of civil society for the equalization of opportunities and for environmental accessibility form part of what might be characterized "next practices" in technical cooperation by the United Nations system, which are central to achieving the aim, identified in General Assembly resolution 48/99, of 20 December 1993, of achieving a "society for all" by 2010.

31. Policy guidance on technical cooperation activities and persons with disabilities is provided by the *World Programme of Action concerning Disabled Persons*. Technical cooperation is one of the international activities identified in the *World Programme* to further its goals of the full participation of persons with disabilities in social life and development and equality.[41] Technical and economic cooperation are also among the set of implementation measures presented in the Standard Rules, viz. Rule 21 (Technical and economic cooperation).[42] The initiative of Mexico at the fifty-sixth session of the General Assembly concerning a comprehensive and integral convention on the rights of persons with disabilities in the context of development provides added emphasis to the policy basis for capacity-building for the equalization of opportunities as a mainstream development cooperation issue, for instance in both triennial policy reviews of operational activities for development considered by the General Assembly[43] and the programming guidelines of United Nations funds and programmes. Persons with

disabilities are not currently a topic elaborated in the procedures for formulating the United Nations Development Assistance Framework (UNDAF) or the common country assessment (CCA), which necessarily affects resource allocations to build national capacities for the equalization of opportunities.

32. Technical cooperation activities are components of larger development efforts designed and implemented by Governments in accordance with national policies and priorities. Technical cooperation produces, by definition, an intermediate product whose aims include strengthened and improved national capacities and institutions for self-reliant development. The test of a technical cooperation activity is the extent to which there is effective and sustained follow-up, as well as replication to other areas, sectors and constituencies on the basis of equality. Reinforcing the disability perspective in mainstream technical cooperation will require action at several levels: policy-level decisions on the part of Governments; procedural decisions on harmonization and simplification by concerned members of the United Nations system; and the provision of opportunities for full and effective participation by persons with disabilities as development agents and beneficiaries. A strategic framework to reinforce the disability perspective in mainstream technical cooperation activities would include the following considerations:

(a) *Policy aspects*. Objectives identified to further the disability dimension in technical cooperation must be linked clearly with national development objectives and priorities, including the outcomes of major United Nations conferences and summits. Objectives formulated with specific reference to persons with disabilities should be presented as integral and not as an adjunct to overall development concerns and purposes. The objective statement should address the question of the resource implications of objectives targeted to a specific social group, as opposed to the benefits of mainstream approaches. Since sustainable technical cooperation follow-up and replication require an unambiguous commitment on the part of Governments, the objective statement must be consistent and supportive of mainstream national development policies and priorities;

(b) *Participation*. Full participation and equality are the goals adopted by the international community for the World Programme of Action concerning Disabled Persons. Participation of persons with disabilities in decisions that affect their livelihoods and well-being is an integral part of a broad human rights framework for development. Participation in this sense pertains to involvement in developmental decision-making, contributing to developmental efforts and equal sharing in the results of development. Major United Nations conferences and summits have addressed the situation of persons with disabilities with reference to a range of substantive concerns and not solely as issues specifically related to disability. As a result of the initiative of Mexico at the fifty-sixth session of the General Assembly concerning a comprehensive and integral convention on the rights of persons with disabilities the human rights of persons with disabilities is now recognized as an essential prerequisite for advancing the rights of all;

(c) *Institutions*. Successful technical cooperation requires effective multi-level institutional mechanisms to plan, organize and deliver technical cooperation inputs and to receive these inputs and put them to use by, for and with the intended beneficiaries. Since technical cooperation often involves the introduction of new concepts, methods, technologies and procedures to an existing development setting, it is important that local organizations, including organizations of persons with

disabilities, be involved in all aspects of planning, design and implementation of technical cooperation activities and their follow-up. Such involvement builds stakeholders and serves to ensure that technical cooperation activities are consistent with local needs, socio-cultural conditions, and technical, managerial and financial capacities prevailing;

(d) *Resources*. While the local level can make important resource contributions to technical cooperation activities, it should be recognized that the majority of persons with disabilities in developing countries and countries with economies in transition are poor and reside mainly in rural areas. Since many persons with disabilities may have limited capacities to contribute either material or in kind resources to technical cooperation activities, technical cooperation policies and plans need to include explicit consideration of both the income and employment implications for intended beneficiaries and the apportionment of the costs involved in project implementation and follow-up;

(e) *Capacity-building*. For mainstream technical cooperation to contribute to enhanced participation, on the basis of equality, of persons with disabilities as development agents and beneficiaries, there is a need for systematic capacity-building and institutional development among (1) staff of the technical cooperation programmes and agencies concerned (planning and management level), (2) staff at the field (implementation) level, and (3) persons with disabilities (beneficiary level);

(f) *Monitoring and evaluation*. Monitoring and evaluation of operational activities for development is a major concern of the United Nations system, particularly as this pertains to the simplification and harmonization of procedures and to ensuring more effective and rapid dissemination of monitoring and evaluation findings to improve performance and strengthen national capacities.[44] One factor that may enhance monitoring and evaluation procedures would be the introduction of disability-sensitive decision points in an early revision of the United Nations Development Assistance Framework process. Reinforcing the disability dimension in mainstream technical cooperation would involve at least three issues in ex-post evaluations: (1) how were persons with disabilities involved in decisions on the planning, design and execution of mainstream technical cooperation activities; (2) what benefits have persons with disabilities achieved from technical cooperation; how were these distributed, and what were the costs associated with the activities and by whom were these borne; and what are the project outcomes from the disability perspective; (3) has there been project follow-up; and, if so, who was involved in this decision and has the project experience been generalized to a wider range of development constituencies, sectors or geographical areas.

Notes

[1] Rodrigo Jiménez Sandoval, *Eliminando Barreras, Construyendo Oportunidades* (Naciones Unidas, ILANUD, San José, Costa Rica, 1997).

[2] A/56/PV.44.

[3] See Hahn, Harlan, "The political implications of disability definitions and data", *Disability Policy Studies*, vol. 4, No. 2.

[4] Ibid.

[5] Rioux, Marcia H., "Disability: the place of judgement in a world of fact", *Journal of Intellectual*

Disability Research, vol. 41, No. 2).

[6] Oliver, Michael, "Changing the social relations of research production", *Disability, Handicap and Society*, vol. 7, No. 2.

[7] Brown, Scott Campbell, "Methodological paradigms that shape disability research", in Gary L. Albrecht, Katharine D. Seelman and Michael Bury, eds., *Handbook of Disability Studies* (Thousand Oaks, Sage Publications, 2001).

[8] Pechansky, R., and C. Thomas, "The concept of access: definition and relation to customer satisfaction", *Medical Care*, vol. 19, No. 2.

[9] Ibid.

[10] Whiteneck, Gale G., Patrick Fougeyrollas and Kenneth A. Gerhart, "Elaborating the model of disablement", in Marcus J. Fuher, ed., *Assessing Medical Rehabilitation Practices: the Promise of Outcomes Research* (Baltimore, Paul H. Brookes Publishing, 1997).

[11] Ron Mace http://www.design.ncsu.edu/cud/univ_design/ud.htm.

[12] World Health Organization, *International Classification of Impairments, Disabilities and Handicaps* (Geneva, 1980).

[13] Report of a consultative expert meeting on critical issues and trends related to disability and human rights: emerging issues and concepts, York University, Toronto, 17-19 June 2002.

[14] Ibid., para. 46.

[15] Robert L. Metts, "Planning for disability"; paper presented at a panel discussion on independent living of persons with disabilities, United Nations, 3 December 1998.

[16] *Official Records of the Economic and Social Council, 1998, Supplement No. 6* (E/1998/26), chap. I, paras. 38-63.

[17] *Proceedings of the First World Conference of Disabled Peoples' International*, Singapore, 30 November-4 December 1981.

[18] United Nations *Guidelines and principles for the development of disability statistics* (2001).

[19] The ICIDH causal model also fails to capture the fact that handicap can lead to the creation of disability as well as impairment.

[20] "Acquire" follows the usage of Professor Amartya Sen in his analysis of entitlements and capabilities. Professor Sen has argued that "Ultimately, the process of economic development has to be concerned with what people can or cannot do, e.g. whether they can ... read, write and communicate, take part in literary and scientific pursuits." He continues, "A major failing of traditional ... economics has been its tendency to concentrate on supply of goods rather than on ownership and entitlement." Entitlement in this sense "refer to the set of alternative commodity bundles that a person can command in a society using the totality of rights and opportunities that he or she faces." On the basis of entitlement, "a person can acquire some capabilities, i.e., the ability to do this or that (e.g., be well nourished), and fail to acquire some other capabilities." See, Amartya Sen, "Development: which way now?", *The Economic Journal*, vol. 93 (1983). The focus of the developmental approach thus becomes expansion of entitlements for all.

[21] Seelman, Katherine D. "Change and challenge: the integration of the new paradigm of disability into research and practice, a vision for the 21st century: population, health care, technology and employment", paper presented to the National Council on Rehabilitation education conference (Vancouver, 8 March 1998).

[22] Notable work has been carried out by, inter alia, the ILO on employment statistics and indicators, UNESCO on educational statistics and indicators, WHO on health-related statistics and indicators, and UNICEF on statistics on the children and child survival; the regional commissions of the United Nations have major statistical programmes as well.

[23] ICIDH, op. cit.

[24] ICF, op. cit.

[25] *Statistics on Special Population Groups* (United Nations publication, Sales No. E.90.XVII.17).

[26] The United Nations Statistics Division also found that disability approaches lead to higher rates of disability in a population than do impairment approaches. A single question assessing functional limitations associated with a disability typically embraces behaviour associated with a broad range of impairment conditions. For instance, a question about "difficulty climbing stairs" may be due to several impairment conditions. In contrast, impairment approaches generally use more direct questions that relate to specific conditions; for instance, a question about "hearing loss" can determine whether loss is profound and affects one or both ears.

[27] The United Nations Statistics Division has drawn attention to the need to standardize methods of calculating disability rates; for instance, the crude disability rate of impairment should by definition include all disabled persons for the total population in the numerator, and the denominator should include the number of the total population; age-specific disability rates need to maintain standard and comparable age ranges for numerators and denominators.

[28] Metts, Robert L., "An overview of future research in disability and development, unpublished paper (2002).

[29] *Principles and Recommendations for Population and Housing Censuses, Revision 1* (United Nations publication, Sales No. E.98.XVII.8).

[30] Ibid., para. 2.262.

[31] Chamie, Mary. 1992, "A perspective for considering the classification of handicap", unpublished paper (1992); and Scott Campbell Brown, "Revitalizing 'handicap' for disability research", *Journal of Disability Studies*, vol. 4, No. 2.

[32] In connection with the Asian and Pacific Decade of Disabled Persons (1993-2002) goal of promoting accessible environments for all, the Economic and Social Commission for Asia and the Pacific (ESCAP) undertook, with financial and technical support of the Government of Japan (the Ministry of Construction, in particular) a regional project on the promotion of non-handicapping environments for disabled and elderly persons. ESCAP published guidelines (ST/ESCAP/1492) and case studies (ST/ESCAP/1510) of selected national experience in promoting non-handicapping physical environments. ESCAP organized training workshops at Beijing and New Delhi and field-tested trainer guidelines at Bangalore (India), Pattaya (Thailand) and Penang (Malaysia).

[33] Economic and Social Council document E/2000/L.9.

[34] A/57/357, para. 16.

[35] Human Genome Project Information (http://www.ornl.gov/hgmis/).

[36] International League of Societies for Persons with Mental Handicaps, *Just Technology? From principles to practice in bio-ethical issues* (Toronto, Roeher Institute, 1994).

[37] Kass, Leon R., *Life, Liberty and the Defense of Dignity* (San Francisco, Encounter Books, 2002).

[38] Avard, Denise, "New genetics", unpublished paper (2002).

[39] (http://www.agfund.org/).

[40] United Nations document A/54/388/Add.1, "Disability-sensitive development cooperation in the twenty-first century: partnerships and venture grants".

[41] United Nations document A/37/351/Add.1 and Add.1/Corr.1.

[42] General Assembly resolution 48/96 of 20 December 1993, annex, rule 21.

[43] General Assembly resolution 56/201 of 21 December 2001, "Triennial policy review of operational activities for development of the United Nations system", directs special attention to globalization, humanitarian assistance and gender, and to funding operational activities for development and simplification and harmonization of procedures.

[44] See E/2000/46/Add.1, paras. 128-132.